

The Carolina Lupus Study Newsletter

Number 2, September 1997

The Carolina Lupus Study is officially under way, and we have had a very successful first few months in the field. Here is a summary of our experience to date.

CLU Study Progress

Our process involves four main steps: we **receive referrals** of patients from CLU physicians, we **contact** the patients to determine if they are eligible, we **enroll** interested patients into the study, and we **complete** an interview and get a blood sample from patients who agree to participate. In our first 6 months, we have:

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|-----------|-----|------------|
| Received | 112 | referrals |
| Contacted | 94 | |
| Enrolled | 89 | |
| Completed | 82 | interviews |

Few patients have declined to participate, and 91% have agreed to provide a blood sample. The interest and cooperation we have received reflects the dedication of the lupus patients and their interest in contributing to research about this disease.

We have also enrolled 41 representatives of the general population ("controls"). Only 17% of the controls we have contacted have declined to participate, which is a very good indication of the willingness of the people of North Carolina and South Carolina to give of their time to help others.

Our interviewers, **Alesia Sanyika** and **Sara Graham** have logged more than 11,000 miles in their travels in the eastern Carolinas.

Who are the CLU Participants?

Lupus most often affects young women, and this is shown by the make-up of our study participants. Of the patients referred to our study, 93% are female. The average age at diagnosis is 30 years, but ranges from 18 to 81. Most CLU participants were born in North Carolina or South Carolina, but others are from many different parts of the world (including South America, Europe, and Asia). More than half (53%) of CLU patients are African Americans.

What Have We Learned?

We have not undertaken any formal data analysis since it is important to wait until we have enough cases and controls to make valid comparisons. But one very important aspect of what we have learned comes from the participants' comments at the end of the interview. Patients have expressed their worries about the health of family members, stresses in their lives, and concerns about working conditions. These are all issues that we will be able to examine in the Carolina Lupus Study.

Staff Updates

Ella Akin is our new coordinator at Duke, replacing Carmin Cinniger who is heading for medical school. **June Arnold** is at MUSC, but **Laura Lindsey** will be leaving UNC (for Duke of all places). We are sorry to see her go.

For more information, call Ms. Lyle Lansdell at 800-948-7552 (ext 122) or Ms. Alyssa Ghirardelli (ext 143).

CLU Investigators: Glinda S. Cooper, Ph.D., NIEHS
Gary S. Gilkeson, M.D., MUSC
Edward L. Treadwell, M.D., ECU

Mary Anne Dooley, M.D., UNC
Bill St. Clair, M.D., Duke

The **CLU Study Group** continues to grow, and now includes more than 30 private practice rheumatologists and other physicians. We are also working with the residents and faculty at the medical centers.

Carolina Lupus Study Physicians

North Carolina

Private Practice Rheumatology:

H. Vann Austin
Franc. A. Barada
Walter Chmielewski
Duncan Fagundus
Helen Harmon
Robert A. Harrell, III
John L. Harshbarger
G. Wallace Kernodle, Jr.
Elliot J. Kopp
Kara Martin
John L. McCain
Gwenesta B. Melton
David W. Puett
C. Michael Ramsdell
A. Silvia Ross
Gregory F. Schimizzi
Claudia J. Svara
Anne K. Toohey
Randal E. White
Suzanne J. Zorn

Duke University Medical Center:

Nancy B. Allen
Thomas Lang
Elvia Moreta
Bill St. Clair
Dylan Steer
John Sundy

East Carolina University School of Medicine:

Edward L. Treadwell

University of North Carolina at Chapel Hill:

Robert G. Berger
Philip L. Cohen
Mary Anne Dooley
James E. Godwin
Nortin Hadler
John B. Winfield
William Yount

Lincoln Community Health Center:

Faye Banks
Cathleen Melton
Byron Randolph
Evelyn Schmidt

Other North Carolina Physicians:

William Olds
Thomas Speros

South Carolina

Private Practice Rheumatology:

Carlyle Barfield
John Brittis
Walter Bonner
William M. Edwards
Gary E. Fink
Frank E. Harper
Wendy Lee
Holly Mitchell
Alan I. Nussbaum
Georgia Roane
William B. Sheldon

Medical University of South Carolina:

Marcy Bolster
Gary S. Gilkeson
C. W. Legerton, III
Richard Silver
Edwin Smith